Burden of Stroke in Indigenous Western Australians
A Study Using Data Linkage

Judith M. Katzenellenbogen, PhD; Theo Vos, PhD; Peter Somerford, MSc; Stephen Begg, MPH; James B. Semmens, PhD; James P. Codde, PhD

Background and Purpose—Despite the disproportionate burden of cardiovascular disease among indigenous Australians, information on stroke is sparse. This article documents the incidence and burden of stroke (in disability-adjusted life years) in indigenous and non-indigenous people in Western Australia (1997–2002), a state resident to 15% of indigenous Australians comprising 3.4% of the population of Western Australia.

Methods—Indigenous and non-indigenous stroke incidence and excess mortality rates were estimated from linked hospital and mortality data, with adjustment for nonadmitted events. Nonfatal burden was calculated from nonfatal incidence, duration (modeled from incidence, excess mortality, and remission), and disability weights. Stroke death counts formed the basis of fatal burden. Nonfatal and fatal burden were summed to obtain disability-adjusted life years, by indigenous status.

Results—The total burden was 55,099 and 2,134 disability-adjusted life years in non-indigenous and indigenous Western Australians, respectively. The indigenous to non-indigenous age-standardized stroke incidence rate ratio (≥15 years) was 2.6 in males (95% CI, 2.3–3.0) and 3.0 (95% CI, 2.6–3.5) in females, with similar rate ratios of disability-adjusted life years. The burden profile differed substantially between populations, with rate ratios being highest at younger ages.

Conclusions—The differential between indigenous and non-indigenous stroke burden is considerable, highlighting the need for comprehensive intersectoral interventions to reduce indigenous stroke incidence and improve outcomes. Programs to reduce risk factors and increase access to culturally appropriate stroke services are required. The results here provide the quantitative basis for policy development and monitoring of stroke outcomes. (Stroke. 2011;42:1515-1521.)

Key Words: cerebrovascular accident ■ epidemiology ■ health policy ■ indigenous

The indigenous population of Australia (Aboriginal and Torres Strait Islander peoples) has a disproportionate burden of disease, exemplified by an 11-year lower life expectancy compared with other Australians, that reflects entrenched historic, cultural, socioeconomic, and political disadvantage. The morbidity profile for indigenous Australians is characterized by high rates of cardiovascular diseases (including rheumatic heart disease), diabetes, and end-stage renal failure, with cardiovascular diseases being the leading cause of death. Western Australia (WA) is home to 15% of indigenous Australians (2003 WA population 68,661) who are spread across a vast area encompassing all levels of remoteness and with substantial heterogeneity with respect to language group and culture.

Stroke contributes ~3% of the indigenous health gap in Australia. Until recently, the impact (burden) of stroke on the indigenous population was estimated using mortality and hospitalization rates only, potentially underestimating the burden on communities. Quantification of disease rates is challenging, with under-identification of indigenous people in hospital and death data and small case numbers often hampering accurate estimates. Consequently, detailed analyses of the indigenous burden of stroke using alternative measures are rare. However, in WA, the study of the health of the population is facilitated by a well-established, comprehensive health data linkage system that allows detailed epidemiological investigation of particular diseases.

In this article, we estimate the burden of stroke in indigenous compared with non-indigenous Western Australians (aged 15 years or older) pertaining to a 5-year period between July 1997 and June 2002, using the Disability Adjusted Life Year (DALY) metric. This composite burden of disease...
Table 1. Data Components, Sources, and Assumptions Used in Calculating Disability-Adjusted Life Years for Stroke

<table>
<thead>
<tr>
<th>Component Data</th>
<th>Data Sources</th>
<th>Assumptions</th>
<th>Calculation</th>
</tr>
</thead>
<tbody>
<tr>
<td>YLL 1. Stroke death counts, by age, sex, and indigenous status</td>
<td>Mortality register</td>
<td>Stroke-coded deaths capture fatal stroke</td>
<td>Death counts × standard lease (age-specific)</td>
</tr>
<tr>
<td>2. Global standard LE at each age</td>
<td>Global Burden of Disease Study 1994</td>
<td>Life tables selected representing optimal mortality profile globally</td>
<td></td>
</tr>
<tr>
<td>YLD 1. Nonfatal incidence (28-d survivors)</td>
<td>• Unit record linked hospital and death data</td>
<td>• 8-y clearance identifies “first-ever” cases</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Admission proportions from PCSS to adjust for out-of-hospital cases</td>
<td>• Perth admission proportions apply to indigenous population</td>
<td></td>
</tr>
<tr>
<td>2. Duration</td>
<td>Modelled in DisMod: provides analytic solution to a set of differential equations describing the relationship between total mortality and 3 rates: case fatality, incidence, remission</td>
<td>• DisMod assumes mortality from all other causes is independent of the disease being modeled</td>
<td>YLD = Incidence × duration × DW</td>
</tr>
<tr>
<td></td>
<td>Input 1: Nonfatal incidence Input 2: Remission Input 3: EMR = mortality rate in prevalent stroke cases minus population mortality rate</td>
<td>• Conceptual model of DisMod is a multistate life table</td>
<td></td>
</tr>
<tr>
<td>3. DW not reported in detail in this article</td>
<td>Disability data from PCSS. Mapped to EuroQol. Adjusted for prestroke function. Regression equation to predict age-specific DW</td>
<td>Remission = zero Excess mortality approximates case fatality rate</td>
<td></td>
</tr>
</tbody>
</table>

**Materials and Methods**

The key source of empirical data was the WA Data Linkage System, allowing the linkage of administrative health data from ~7 core datasets. Data from a 5-year period (July 1997–June 2002) were aggregated to increase case numbers. To address under-identification of indigenous cases in administrative records, any stroke case identified as indigenous on any hospital admission between 1988 and 2002 or on the death record was coded as indigenous.

Table 1 summarizes the components of the DALY calculated here, including associated data sources and assumptions. For the fatal component, stroke (International Classification of Diseases version 10 codes I60–I69) deaths were extracted from the WA mortality database and age-specific deaths were converted to years of life lost by multiplying these by the standard life expectancies at age of death based on the Global Burden of Disease standard. For nonfatal burden, YLD were calculated as the product of age-specific and sex-specific nonfatal incidence counts, duration of illness, and stroke-specific disability weights (DW). Because of the high initial fatality after stroke, nonfatal incident stroke was defined as patients with first-ever stroke cases surviving at least 28 days. Each YLD element was estimated differently, as described.

**Incidence**

Incidence was estimated from linked hospital and mortality data. First, all admissions to WA private and public hospitals coded to acute stroke (International Classification of Diseases version 10 codes I60, I61, I63, I64, and corresponding International Classification of Diseases version 9 codes) between 1988 and 2002 were extracted from the Hospital Morbidity Data Collection. These codes conform to guidelines for monitoring the incidence of stroke in Australia. Within-hospital data linkage allowed identification of first-ever hospital admissions for acute stroke pertaining to the 1997 to 2002 study period, using an 8-year clearance period to exclude cases of previous stroke admissions, thus minimizing inclusion of existing/prevalent cases. Second, individual-level mortality records were merged with hospital records to ascertain survival status, identifying those incident cases who survived to 28 days. Next, data from the 1995 to 1996 Perth Community Stroke Study were used to adjust incident counts for out-of-hospital strokes (assuming admission proportions were 91% [age 15–74 years] and 88% [age 75 years and older]) and to estimate the proportion of out-of-hospital 28-day survivors. In- and out-of-hospital estimates were summed to provide population-based indigenous and non-indigenous total and nonfatal incidence by age and sex.

**Duration**

Duration was calculated separately for indigenous and non-indigenous people in DisMod II, specialized computer software that models unknown disease measures from at least 3 known estimates, producing consistent estimates of incidence, prevalence, case fatality, remission, and duration. Assuming zero remission and using the nonfatal incidence calculated, the third input comprised the excess mortality rate (EMR), reflecting the mortality risk in stroke patients over and above the all-cause mortality risk in the general population. Age-specific and sex-specific EMR were calculated for prevalent cases, defined as those recorded in the hospital admission dataset since 1988 for acute stroke or sequelae of stroke (I69), who had survived to 28 days, and who were still alive sometime in the 5-year study period. The mortality risk in patients was calculated from the ratio of deaths (attributed to age at death) and person-years of follow-up during this observation period. The all-cause mortality in the non-indigenous population was estimated from WA mortality statistics, whereas that for indigenous people was based on all-Australian indigenous estimates. Because of uncertainty of indigenous estimates at older ages, trend lines were plotted in Excel (Microsoft) using age-group-specific EMR up to 74 years as inputs and extrapolating to older ages. Because male and female EMR age
trends differed, a power trend line was used for males and a polynomial trend line was used for females.

**DW**
Quality-adjustment of years lived with disease are dealt with by the use of DW. These values lie between 0 (representing perfect health) and 1 (representing death) and are numerically equal to the complement of preference-based quality-of-life weights (DW = 1 − quality-of-life weight). Age-group-specific DW from a previous WA study based on disability data from a community stroke study and reflecting stroke-related disability, adjusted for prestroke disability, were utilized here for both indigenous and non-indigenous analyses. DW estimated at 4 months (mean DW, 0.38) was applied to YLD for the first year after stroke and DW estimated at 12 months (mean DW, 0.31) was applied to the remaining duration.

**YLD**
YLD were discounted (deflated) at 3% per year to take into account society’s preference for short-term benefits, as is standard in Global Burden of Disease studies. Uncertainty intervals (95%) for nonfatal incidence and EMR were calculated using Monte Carlo simulation (bootstrap) methods in @Risk software. This software allows the uncertainty from various sources to be captured at once, providing uncertainty intervals that can be interpreted in a similar way to confidence intervals. Nonfatal incident counts and the observed deaths were assumed to follow a Poisson distribution. Uncertainty intervals for YLD were calculated in DisMod II.

**Age-Standardized Rates and Rate Ratios**
Summary indigenous and non-indigenous age-standardized rates and rate ratios were estimated by the direct method for incidence, YLD, YLL, and DALY using the World Health Organization World Standard population, a population age structure commonly used when comparing rates between populations of varying age distributions. This study was performed under the auspices of the epidemiology branch of the WA Department of Health. Ethics approval for the use of de-identified linked records was obtained through a confidentiality process allowing the epidemiology branch to undertake research using the WA Data Linkage System housed in the Department of Health.

**Results**

**Incidence**
A total of 378 indigenous and 10 285 non-indigenous people were identified through the hospital records as having had a first-ever stroke in the 5-year study period, with 80% of each group surviving to 28 days. After adjustment for out-of-hospital cases, 419 indigenous and 11 441 non-indigenous cases contributed to total rates, whereas 337 indigenous and 8 993 non-indigenous cases contributed to nonfatal incidence rates.

Total and nonfatal incidence rates increased with age, with indigenous rates being significantly higher than non-indigenous rates at all ages to 74 years (Table 2). Indigenous age-standardized rates 15 years were 2.6-times (95% CI, 2.3–3.0) higher in males and 3.0-times (95% CI, 2.6–3.5) higher in females compared with their non-indigenous counterparts. Rate ratios were even higher (males, 4.6; females, 5.8) when age was restricted to 15 to 64 years. Disparities were of a similar magnitude for nonfatal stroke incidence.

**Excess Mortality Rates and Duration**
EMR increased and duration decreased with age for both indigenous and non-indigenous people (Figure 1). EMR were higher in indigenous than in non-indigenous people at all ages, with disparities decreasing with age. The average survival of first-ever stroke was 13 years lower in indigenous males and 7 years lower in indigenous females compared with their non-indigenous counterparts in the 15- to 24-year age group. In the 75-year and older age group, differences in duration between indigenous and non-indigenous people were small.

**Burden of Stroke**
More than 60% of indigenous nonfatal stroke burden occurred in the 15- to 54-year age group, compared with 24% in the non-indigenous population (Figure 2). Fatal burden dominated the profile, contributing 67% of the male and 53% of the female indigenous DALY and 57% of male and 66% of the female non-indigenous DALY. Unlike that for non-indigenous people, the mortality burden was highest and fairly evenly spread between 35 and 74 years in indigenous people.

Age-specific DALY rates increased with age to age 74 years in indigenous and non-indigenous males and females (Table 3). In the 75-year and older age group, non-indigenous rates continued to increase. Indigenous rates were substantially higher than non-indigenous rates at all ages younger than 75 years. Indigenous age-standardized DALY rates were 3-times higher for both sexes than corresponding non-indigenous rates (Table 2). When restricting the analysis to ages 15 to 64 years, DALY rates were 5-times higher in indigenous people.

**Discussion**
Our results provide evidence of the substantially higher burden of stroke and distinct epidemiological pattern in indigenous compared with non-indigenous Western Australians. Differentials pertaining to the population aged 15 to 64 years cover the ages for which data quality was best and inequalities were the most substantial. The elevated burden is reflected not only in the composite DALY estimates but also in the epidemiological components underlying DALY. As the first detailed population-based estimates of indigenous stroke incidence and burden in Australia (and incorporated in a recent national burden of disease report), these findings highlight the need for comprehensive intersectoral interventions to reduce indigenous incidence and improve stroke outcomes.

The disparity in stroke incidence is reflected in an age-standardized indigenous incidence rate 2.8-times that of non-indigenous Western Australians, increasing to 5.1 in ages 15 to 64 years. These findings are substantiated by other indigenous health statistics in Australia that reflect stroke age-standardized hospitalization rates that are 2.1-times those and stroke death rates that are 1.9-times those of non-indigenous Australians. EMR were also substantially higher in the indigenous population, even with the extremely high background population mortality. The high EMR and the lower life expectancy resulted in much lower indigenous duration estimates compared with that for non-indigenous people, particularly among younger males.
The high levels of total stroke burden in indigenous Western Australians concurs with the findings of an analysis in the Northern Territory, where the Aboriginal population had an all-cause DALY rate 2.5-times that of the non-Aboriginal population, with rate ratios increasing to 4.1 in the 35- to 54-year age group. Cardiovascular disease was the highest contributor to total indigenous disease burden in that study; stroke was not reported separately. Outside Australia, differentials in stroke burden also have been shown for ethnic minorities. A 2-fold ethnic differential in stroke incidence was reported in urban population-based studies in the United States and United Kingdom, with greater differentials in younger people. Differentials in stroke mortality were somewhat lower than differentials in incidence among blacks in the United States compared with the general population. Maori and Pacific Islander people experience higher incidence, disability, and mortality from stroke than other New Zealanders. In North America, quantification of differentials pertaining to indigenous populations has proved unreliable because of difficulties in identifying indigenous cases in routine data.

The uncertainties in our estimates reflect the challenges of obtaining good-quality epidemiological data for indigenous people. Although our case numbers were small, the percentage of indigenous cases having consistent indigenous codes on the linked hospital and mortality records (84%) corresponds closely with the proportion of correct codes found in the 2000 WA validation study of indigenous coding on hospital records. Consequently, our estimates are less likely to be underestimated as a result of under-identification. A number of assumptions also had to be made in the calculation of indigenous YLD. First, data from an urban population-based stroke study were used to account for out-of-hospital fatal cases. A pilot study to evaluate this assumption found little evidence of difference by Aboriginality and residential location, suggesting that its use in this study is acceptable, given the lack of more definitive data. Second, DW were assumed to be the same for the indigenous population as the

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Non-Indigenous</th>
<th>Indigenous</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>Rate</td>
</tr>
<tr>
<td>15–34</td>
<td>141</td>
<td>10</td>
</tr>
<tr>
<td>35–54</td>
<td>637</td>
<td>47</td>
</tr>
<tr>
<td>55–64</td>
<td>854</td>
<td>208</td>
</tr>
<tr>
<td>65–74</td>
<td>1523</td>
<td>553</td>
</tr>
<tr>
<td>75 or older</td>
<td>2514</td>
<td>1490</td>
</tr>
</tbody>
</table>

ASR† indicates age-standardized rate; CI, confidence interval; UI, uncertainty interval.
*UI indicates uncertainty interval calculated in DisMod II, derived from bootstrap methods, can be interpreted similar to confidence intervals.
†ASR indicates age-standardized rate standardized to World Health Organization Standard Population.
rest of WA, but indigenous people generally have more comorbidity, may have a different severity profile, and may value health-related quality of life differently. However, the DW utilized in this analysis account for prestroke comorbidity and disability. Additionally, the global approach advocates using the same DW across different socioeconomic and cultural contexts to allow valid comparisons between populations.

Despite these limitations and assumptions, the results document extreme differentials by Aboriginality in stroke...
burden, the scale of which has been mirrored elsewhere for other conditions.\textsuperscript{1,4,6,20,29} The number of individuals surviving stroke and living with a disability is a major concern. The underlying causes of these health disparities are complex, with socioeconomic, historical, and environmental disadvantage operating through behavioral and physiological risk factors influencing health outcomes. Although this study was not designed to attribute causality, a range of preventive and therapeutic strategies are warranted. It is apparent that the multiple determinants of indigenous health in general and stroke specifically require a committed, long-term, multi-pronged, and intersectoral response.\textsuperscript{30,31} Within the health sector, a comprehensive, integrated, and culturally sensitive primary health care program is required, providing training and support for indigenous and non-indigenous health care workers.\textsuperscript{30,31} Reducing highly prevalent behavioral factors associated with stroke (for example, smoking and substance abuse) and management of physiological risk factors, including hypertension, diabetes, and rheumatic heart disease, have been identified as priorities.\textsuperscript{29} In WA, indigenous needs in the acute stroke care context were found to relate to dissemination of knowledge about stroke and services, addressing cultural needs, geographical isolation, access to services, and improved recognition of the impact on and support for families.\textsuperscript{31} Access to acute care and rehabilitation, particularly stroke units outside the metropolitan areas, is considered the foundation of secondary and tertiary prevention.\textsuperscript{31}

Policies to address the indigenous disease burden have been disappointing\textsuperscript{32} and indigenous health remains under-funded relative to the need.\textsuperscript{32,33} The Commonwealth “Closing the Gap” strategy\textsuperscript{34} is promising in terms of increasing funding and focus. Estimates of the burden of stroke, as reported here, can provide the quantitative base from which to monitor stroke outcomes.\textsuperscript{20}

### Acknowledgments

The Data Linkage Branch within the Western Australia Department of Health linked the hospitalization and mortality data using the Western Australia Data Linkage System.

### Sources of Funding

Judith Katzenellenbogen was supported by a postgraduate scholarship from the National Health and Medical Research Council (Australia).

### Disclosures

None.

### References


7. Australia Institute of Health and Welfare. Data quality of Aboriginal and Torres Strait Islander peoples. Canberra, Australia: AIHW; 2004;catalog number number HW179.


Burden of Stroke in Indigenous Western Australians: A Study Using Data Linkage
Judith M. Katzenellenbogen, Theo Vos, Peter Somerford, Stephen Begg, James B. Semmens and James P. Codde

Stroke. 2011;42:1515-1521; originally published online April 14, 2011;
doi: 10.1161/STROKEAHA.110.601799
Stroke is published by the American Heart Association, 7272 Greenville Avenue, Dallas, TX 75231
Copyright © 2011 American Heart Association, Inc. All rights reserved.
Print ISSN: 0039-2499. Online ISSN: 1524-4628

The online version of this article, along with updated information and services, is located on the
World Wide Web at:
http://stroke.ahajournals.org/content/42/6/1515

Permissions: Requests for permissions to reproduce figures, tables, or portions of articles originally published
in Stroke can be obtained via RightsLink, a service of the Copyright Clearance Center, not the Editorial Office.
Once the online version of the published article for which permission is being requested is located, click
Request Permissions in the middle column of the Web page under Services. Further information about this
process is available in the Permissions and Rights Question and Answer document.

Reprints: Information about reprints can be found online at:
http://www.lww.com/reprints

Subscriptions: Information about subscribing to Stroke is online at:
http://stroke.ahajournals.org/subscriptions/